

105TH CONGRESS
2D SESSION

H. R. 3299

To establish limitations with respect to the disclosure and use of genetic information in connection with group health plans and health insurance coverage, to provide for consistent standards applicable in connection with hospital care and medical services provided under title 38 of the United States Code, to prohibit employment discrimination on the basis of genetic information and genetic testing, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 26, 1998

Mrs. LINDA SMITH of Washington introduced the following bill; which was referred to the Committee on Commerce, and in addition to the Committees on Education and the Workforce, and Veterans' Affairs, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To establish limitations with respect to the disclosure and use of genetic information in connection with group health plans and health insurance coverage, to provide for consistent standards applicable in connection with hospital care and medical services provided under title 38 of the United States Code, to prohibit employment discrimination on the basis of genetic information and genetic testing, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Family Genetic Pri-
3 vacy and Protection Act”.

4 **SEC. 2. PROHIBITION OF HEALTH INSURANCE DISCRIMINA-**
5 **TION ON THE BASIS OF GENETIC INFORMA-**
6 **TION.**

7 (a) GROUP COVERAGE.—

8 (1) AMENDMENTS TO PUBLIC HEALTH SERVICE
9 ACT.—

10 (A) INCLUSION OF GENETIC TESTING IN
11 NONDISCRIMINATION REQUIREMENTS.—Section
12 2702(a)(1)(F) of the Public Health Service Act
13 (42 U.S.C. 300gg–1(a)(1)(F)), as added by sec-
14 tion 102(a) of Health Insurance Portability and
15 Accountability Act of 1996, is amended by in-
16 serting “(or a request for, or receipt of, genetic
17 information or a genetic test)” after “genetic
18 information”.

19 (B) PROHIBITIONS AGAINST USE AND DIS-
20 CLOSURE OF GENETIC INFORMATION.—Subpart
21 2 of part A of title XXVII of the Public Health
22 Service Act, as amended by section 703(a) of
23 Public Law 104–204, is amended by adding at
24 the end the following new section:

1 **“SEC. 2706. PROHIBITIONS AGAINST USE AND DISCLOSURE**
2 **OF GENETIC INFORMATION.**

3 “(a) PROHIBITION OF USE OF GENETIC INFORMA-
4 TION.—A group health plan, and a health insurance issuer
5 offering health insurance coverage in connection with a
6 group health plan, may not use genetic information to re-
7 ject, deny, limit, cancel, refuse to renew, establish differen-
8 tial rates or premium payments for, or otherwise affect
9 benefits provided under the plan or health insurance cov-
10 erage offered in connection with the plan.

11 “(b) PROHIBITION OF DISCLOSURE OF GENETIC IN-
12 FORMATION.—

13 “(1) IN GENERAL.—Except as provided in para-
14 graph (2), regardless of the manner in which genetic
15 information was received, or of the source of such
16 information, including information received from an
17 individual, a health insurance issuer in connection
18 with health insurance coverage offered in connection
19 with a group health plan and a group health plan
20 may not disclose or be compelled (by subpoena or
21 any other means) to disclose genetic information
22 about an individual unless such disclosure is specifi-
23 cally authorized by the individual involved or the
24 legal representative of the individual through a writ-
25 ten authorization which includes a description of the
26 information being disclosed, the name of the individ-

1 ual or entity to whom the disclosure is being made,
2 and the purpose of the disclosure.

3 “(2) EXCEPTIONS.—Notwithstanding para-
4 graph (1), genetic information concerning an indi-
5 vidual may be disclosed if such disclosure—

6 “(A) is authorized under Federal or State
7 criminal laws relating to the identification of in-
8 dividuals, or as is necessary for the purpose of
9 a criminal or death investigation, a criminal or
10 juvenile proceeding, an inquest, or a child fatal-
11 ity review by a multidisciplinary child abuse
12 team;

13 “(B) is required under the specific order of
14 a Federal or State court;

15 “(C) is authorized under Federal or State
16 law for the purpose of establishing paternity; or

17 “(D) is for the purpose of identifying bod-
18 ies.

19 “(3) APPLICATION OF SUBSECTION.—The pro-
20 hibitions of this subsection shall apply to any re-
21 disclosure by any entity after another entity has dis-
22 closed the genetic information.”.

23 (C) DEFINITIONS.—Section 2791(d) of the
24 Public Health Service Act (42 U.S.C. 300gg—

1 91(d)) is amended by adding at the end the fol-
2 lowing new paragraph:

3 “(15) GENETIC INFORMATION; GENETIC
4 TEST.—

5 “(A) GENETIC INFORMATION.—The term
6 ‘genetic information’ with respect to an individ-
7 ual means information about the genes of the
8 individual or a member of the individual’s fam-
9 ily or about any gene products or inherited
10 characteristics that may derive from the indi-
11 vidual or a member of the individual’s family.

12 “(B) GENETIC TEST.—The term ‘genetic
13 test’ means a test for determining the presence
14 or absence of genetic characteristics in an indi-
15 vidual, including tests of nucleic acids such as
16 DNA, RNA, and mitochondrial DNA, chro-
17 mosomes, or proteins in order to diagnose a ge-
18 netic characteristic.”.

19 (D) CONFORMING AMENDMENT.—Section
20 2723(c) of such Act (42 U.S.C. 300gg–23(c)), as
21 amended by section 604(b)(2) of Public Law 104–
22 204, is amended by striking “section 2704” and in-
23 serting “sections 2704 and 2706”.

24 (2) ERISA AMENDMENTS.—

(A) INCLUSION OF GENETIC TESTING IN
NONDISCRIMINATION REQUIREMENTS.—Section
702(a)(1)(F) of the Employee Retirement In-
come Security Act of 1974 (29 U.S.C.
1182(a)(1)(F)), as added by section 101(a) of
Health Insurance Portability and Accountability
Act of 1996, is amended by inserting “(or a re-
quest for, or receipt of, genetic information or
a genetic test)” after “genetic information”.

(B) PROHIBITION AGAINST USE AND DIS-
CLOSURE OF GENETIC INFORMATION.—Subpart
B of part 7 of subtitle B of title I of the Em-
ployee Retirement Income Security Act of 1974,
as amended by section 702(a) of Public Law
104–204, is amended by adding at the end the
following new section:

**“SEC. 713. PROHIBITION AGAINST USE AND DISCLOSURE
OF GENETIC INFORMATION.**

“(a) PROHIBITION OF USE OF GENETIC INFORMA-
TION.—A group health plan, and a health insurance in-
surer offering health insurance coverage in connection
with a group health plan, may not use genetic information
to reject, deny, limit, cancel, refuse to renew, increase the
rates of, or otherwise affect benefits provided under the

1 plan or health insurance coverage offered in connection
2 with the plan.

3 “(b) PROHIBITION OF DISCLOSURE OF GENETIC IN-
4 FORMATION.—

5 “(1) IN GENERAL.—Except as provided in para-
6 graph (2), regardless of the manner in which genetic
7 information was received, or of the source of such
8 information, including information received from an
9 individual, a health insurance issuer in connection
10 with health insurance coverage offered in connection
11 with a group health plan and a group health plan
12 may not disclose or be compelled (by subpoena or
13 any other means) to disclose genetic information
14 about an individual unless such disclosure is specifi-
15 cally authorized by the individual involved or the
16 legal representative of the individual through a writ-
17 ten authorization which includes a description of the
18 information being disclosed, the name of the individ-
19 ual or entity to whom the disclosure is being made,
20 and the purpose of the disclosure.

21 “(2) EXCEPTIONS.—Notwithstanding para-
22 graph (1), genetic information concerning an indi-
23 vidual may be disclosed if such disclosure—

24 “(A) is authorized under Federal or State
25 criminal laws relating to the identification of in-

dividuals, or as is necessary for the purpose of a criminal or death investigation, a criminal or juvenile proceeding, an inquest, or a child fatality review by a multidisciplinary child abuse team;

“(B) is required under the specific order of a Federal or State court;

“(C) is authorized under Federal or State law for the purpose of establishing paternity; or

“(D) is for the purpose of identifying bodies.

“(3) APPLICATION OF SUBSECTION.—The prohibitions of this subsection shall apply to any redisclosure by any entity after another entity has disclosed the genetic information.”.

(C) DEFINITIONS.—Section 733(d) of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1186(d)) is amended by adding at the end the following new paragraph:

“(5) GENETIC INFORMATION; GENETIC TEST.—

“(A) The term ‘genetic information’ with respect to an individual means information about the genes of the individual or a member of the individual’s family or about any gene products or inherited characteristics that may

1 derive from the individual or a member of the
2 individual's family.

3 “(B) The term ‘genetic test’ means a test
4 for determining the presence or absence of ge-
5 netic characteristics in an individual, including
6 tests of nucleic acids such as DNA, RNA, and
7 mitochondrial DNA, chromosomes, or proteins
8 in order to diagnose a genetic characteristic.”.

9 (D) CONFORMING AMENDMENTS.—(i) Sec-
10 tion 731(c) of such Act (29 U.S.C. 1191(c)), as
11 amended by section 603(b)(1) of Public Law
12 104–204, is amended by striking “section 711”
13 and inserting “sections 711 and 713”.

14 (ii) Section 732(a) of such Act (29 U.S.C.
15 1191a(a)), as amended by section 603(b)(2) of
16 Public Law 104–204, is amended by striking
17 “section 711” and inserting “sections 711 and
18 713”.

19 (iii) The table of contents in section 1 of
20 such Act is amended by inserting after the item
21 relating to section 712 the following new item:

“Sec. 713. Prohibition against use and disclosure of genetic information.”.

22 (b) INDIVIDUAL HEALTH INSURANCE.—Part B of
23 title XXVII of the Public Health Service Act, as amended
24 by section 605(a) of Public Law 104–204, is amended by
25 inserting after section 2751 the following new section:

1 **“SEC. 2752. PROHIBITION AGAINST USE AND DISCLOSURE**
2 **OF GENETIC INFORMATION.**

3 “The provisions of section 2706 shall apply to health
4 insurance coverage offered by a health insurance issuer
5 in the individual market in the same manner as it applies
6 to health insurance coverage offered by a health insurance
7 issuer in connection with a group health plan in the small
8 or large group market.”.

9 (c) TREATMENT OF GENETIC INFORMATION UNDER
10 PROGRAMS ADMINISTERED BY THE DEPARTMENT OF
11 VETERANS’ AFFAIRS.—

12 (1) IN GENERAL.—Subchapter III of chapter
13 73 of title 38, United States Code, is amended by
14 inserting after section 7334 the following new sec-
15 tion:

16 **“§ 7335. Treatment of genetic information**

17 “The Secretary shall prescribe standards, relating to
18 the use and disclosure of genetic information in connection
19 with hospital care and medical services provided under
20 chapter 17 of this title, which are consistent with the
21 standards applicable under section 2706 of the Public
22 Health Service Act (relating to prohibitions against use
23 and disclosure of genetic information) in connection with
24 benefits provided by group health plans and health insur-
25 ance coverage offered by health insurance issuers.”.

1 (2) CONFORMING AMENDMENT.—The table of
2 sections for chapter 73 of title 38, United States
3 Code is amended by inserting after the item relating
4 to section 7334 the following new item:

“7335. Treatment of genetic information.”.

5 (d) EFFECTIVE DATES.—(1) The amendments made
6 by subsection (a) shall apply with respect to group health
7 plans for plan years beginning on or after January 1,
8 1998.

9 (2) The amendments made by subsection (b) shall
10 apply with respect to health insurance coverage offered,
11 sold, issued, renewed, in effect, or operated in the individ-
12 ual market on or after such date.

13 (3) The amendments made by subsection (c) shall
14 apply with respect to hospital care and medical services
15 provided on or after such date.

16 **SEC. 3. PROHIBITION OF EMPLOYMENT PRACTICES IN-**
17 **VOLVING GENETIC INFORMATION.**

18 (a) ACQUISITION AND USE OF GENETIC INFORMA-
19 TION AND GENETIC TESTING.—

20 (1) IN GENERAL.—Subject to paragraph (2), it
21 shall be an unlawful employment practice for an em-
22 ployer—

23 (A) to attempt to acquire, to acquire, or to
24 use the genetic information of an employee or
25 applicant for employment, or

1 (B) to require a genetic test of an em-
2 ployee or applicant for employment,
3 for the purpose of distinguishing among employees
4 or applicants for employment or for the purpose of
5 discriminating against or restricting any right or
6 benefit otherwise due or available to an employee or
7 applicant for employment, in connection with any
8 matter relating to employment or employment op-
9 portunities, including terms and conditions of em-
10 ployment, privileges and benefits for employees, and
11 termination of employment.

12 (2) EXCEPTION.—Paragraph (1) shall not
13 apply with respect to any act described in paragraph
14 (1) with respect to genetic information or any re-
15 quirement described in paragraph (1) for a genetic
16 test if such act or requirement—

17 (A) is job-related and consistent with busi-
18 ness necessity, or

19 (B) is required under Federal or State law.

20 (b) NONDISCLOSURE AND CONFIDENTIALITY OF GE-
21 NETIC INFORMATION.—It shall be an unlawful employ-
22 ment practice for an employer—

23 (1) to allow access to genetic information of
24 employees to any person other than persons whose
25 duties or responsibilities in connection with the em-

1 employer require access to such information for pur-
2 poses consistent with subsection (a), or

3 (2) to establish or maintain access by the em-
4 ployer to an employee's genetic information which
5 has been acquired—

6 (A) by any employee welfare benefit plan
7 established or maintained by the employer in
8 which such employee is a participant (or by any
9 other fiduciary of such a plan), or

10 (B) by any health insurance issuer offering
11 health insurance coverage in connection with a
12 group health plan in which such employee is a
13 participant,

14 without the prior, written, and informed consent of the
15 employee, signed by the employee, setting forth the person
16 or persons to whom access to such information is to be
17 allowed.

18 (c) ENFORCEMENT.—The powers, remedies, and pro-
19 cedures set forth in sections 705 through 709 of the Civil
20 Rights Act of 1964 shall be the powers, remedies, and pro-
21 cedures this section provides to any person alleging a vio-
22 lation of this section.

23 (d) DEFINITIONS.—As used in this section:

24 (1) EMPLOYER; EMPLOYEE.—The terms “em-
25 ployer” and “employee” have the meanings given

1 such terms, respectively, in section 701 of the Civil
2 Rights Act of 1964 (42 U.S.C. 2000e).

3 (2) EMPLOYMENT OR EMPLOYMENT OPPORTU-
4 NITIES.—The term “employment or employment op-
5 portunities” includes job application procedures, hir-
6 ing, advancement, discharge, compensation, job
7 training, or any other term, condition, or privilege of
8 employment.

9 (3) GENETIC INFORMATION.—The term “ge-
10 netic information” with respect to an individual
11 means information about the genes of the individual
12 or a member of the individual’s family or about any
13 gene products or inherited characteristics that may
14 derive from the individual or a member of the indi-
15 vidual’s family.

16 (4) GENETIC TEST.—The term “genetic test”
17 means a test for determining the presence or ab-
18 sence of genetic characteristics in an individual, in-
19 cluding tests of nucleic acids such as DNA, RNA,
20 and mitochondrial DNA, chromosomes, or proteins
21 in order to diagnose a genetic characteristic.

22 (5) OTHER TERMS.—

23 (A) GROUP HEALTH PLAN; HEALTH IN-
24 SURANCE ISSUER; HEALTH INSURANCE COV-
25 ERAGE.—The terms “group health plan”,

1 “health insurance issuer”, and “health insur-
2 ance coverage” have the meanings given such
3 terms, respectively, in section 733 of the Em-
4 ployee Retirement Income Security Act of 1974
5 (29 U.S.C. 1191b(a)).

6 (B) EMPLOYEE WELFARE BENEFIT PLAN;
7 PARTICIPANT.—The terms “employee welfare
8 benefit plan” and “participant” have the mean-
9 ings given such terms, respectively, in section 3
10 of the Employee Retirement Income Security
11 Act of 1974 (29 U.S.C. 1002).

12 **SEC. 4. NATIONAL BIPARTISAN COMMISSION ON THE USE**
13 **OF GENETIC INFORMATION.**

14 (a) ESTABLISHMENT.—There is established a com-
15 mission to be known as the National Bipartisan Commis-
16 sion on the Use of Genetic Information (in this section
17 referred to as the “Commission”).

18 (b) DUTIES OF THE COMMISSION.—The Commission
19 shall make recommendations with respect to the following:

- 20 (1) The development and implementation of
21 standards to provide increased protection for the col-
22 lection, storage, and use of identifiable DNA sam-
23 ples and genetic information obtained from those
24 samples.

1 (2) The development and implementation of ap-
2 appropriate standards for the acquisition and retention
3 of genetic information in all settings, but particu-
4 larly in clinical settings, including appropriate excep-
5 tions.

6 (c) MEMBERSHIP.—

7 (1) NUMBER AND APPOINTMENT.—The Com-
8 mission shall be composed of 17 members, of
9 whom—

10 (A) four shall be appointed by the Presi-
11 dent;

12 (B) six shall be appointed by the Majority
13 Leader of the Senate, in consultation with the
14 Minority Leader of the Senate, of whom not
15 more than 4 shall be of the same political party;

16 (C) six shall be appointed by the Speaker
17 of the House of Representatives, in consultation
18 with the Minority Leader of the House of Rep-
19 resentatives, of whom not more than 4 shall be
20 of the same political party; and

21 (D) one, who shall serve as Chairman of
22 the Commission, appointed jointly by the Presi-
23 dent, Majority Leader of the Senate, and the
24 Speaker of the House of Representatives.

1 (2) EXPERTISE.—It is the sense of the Con-
2 gress that the Commission should include Members
3 with expertise in the following areas:

4 (A) Science and clinical research.

5 (B) Religion.

6 (C) Genetic counseling, and patient advo-
7 cacy and support.

8 (D) Ethics.

9 (E) Law.

10 (3) DEADLINE FOR APPOINTMENT.—Members
11 of the Commission shall be appointed by not later
12 than January 1, 1999.

13 (4) TERMS OF APPOINTMENT.—The term of
14 any appointment under paragraph (1) to the Com-
15 mission shall be for the life of the Commission.

16 (5) MEETINGS.—The Commission shall meet at
17 the call of its Chairman or a majority of its mem-
18 bers.

19 (6) QUORUM.—A quorum shall consist of 8
20 members of the Commission, except that 4 members
21 may conduct a hearing under subsection (e).

22 (7) VACANCIES.—A vacancy on the Commission
23 shall be filled in the same manner in which the origi-
24 nal appointment was made not later than 30 days
25 after the Commission is given notice of the vacancy

1 and shall not affect the power of the remaining
2 members to execute the duties of the Commission.

3 (8) COMPENSATION.—Members of the Commis-
4 sion shall receive no additional pay, allowances, or
5 benefits by reason of their service on the Commis-
6 sion.

7 (9) EXPENSES.—Each member of the Commis-
8 sion shall receive travel expenses and per diem in
9 lieu of subsistence in accordance with sections 5702
10 and 5703 of title 5, United States Code.

11 (d) STAFF AND SUPPORT SERVICES.—

12 (1) EXECUTIVE DIRECTOR.—

13 (A) APPOINTMENT.—The Chairman shall
14 appoint an executive director of the Commis-
15 sion.

16 (B) COMPENSATION.—The executive direc-
17 tor shall be paid the rate of basic pay for level
18 V of the Executive Schedule.

19 (2) STAFF.—With the approval of the Commis-
20 sion, the executive director may appoint such per-
21 sonnel as the executive director considers appro-
22 priate.

23 (3) APPLICABILITY OF CIVIL SERVICE LAWS.—
24 The staff of the Commission shall be appointed with-
25 out regard to the provisions of title 5, United States

1 Code, governing appointments in the competitive
2 service, and shall be paid without regard to the pro-
3 visions of chapter 51 and subchapter III of chapter
4 53 of such title (relating to classification and Gen-
5 eral Schedule pay rates).

6 (4) EXPERTS AND CONSULTANTS.—With the
7 approval of the Commission, the executive director
8 may procure temporary and intermittent services
9 under section 3109(b) of title 5, United States Code.

10 (5) PHYSICAL FACILITIES.—The Administrator
11 of the General Services Administration shall locate
12 suitable office space for the operation of the Com-
13 mission. The facilities shall serve as the head-
14 quarters of the Commission and shall include all
15 necessary equipment and incidentals required for the
16 proper functioning of the Commission.

17 (e) POWERS OF COMMISSION.—

18 (1) HEARINGS AND OTHER ACTIVITIES.—For
19 the purpose of carrying out its duties, the Commis-
20 sion may hold such hearings and undertake such
21 other activities as the Commission determines to be
22 necessary to carry out its duties.

23 (2) STUDIES BY GAO.—Upon the request of the
24 Commission, the Comptroller General shall conduct

1 such studies or investigations as the Commission de-
2 termines to be necessary to carry out its duties.

3 (3) COST ESTIMATES BY CONGRESSIONAL
4 BUDGET OFFICE AND OFFICE OF THE CHIEF ACTU-
5 ARY OF HCFA.—

6 (A) The Director of the Congressional
7 Budget Office or the Chief Actuary of the
8 Health Care Financing Administration, or both,
9 shall provide to the Commission, upon the re-
10 quest of the Commission, such cost estimates as
11 the Commission determines to be necessary to
12 carry out its duties.

13 (B) The Commission shall reimburse the
14 Director of the Congressional Budget Office for
15 expenses relating to the employment in the of-
16 fice of the Director of such additional staff as
17 may be necessary for the Director to comply
18 with requests by the Commission under sub-
19 paragraph (A).

20 (4) DETAIL OF FEDERAL EMPLOYEES.—Upon
21 the request of the Commission, the head of any Fed-
22 eral agency is authorized to detail, without reim-
23 bursement, any of the personnel of such agency to
24 the Commission to assist the Commission in carry-
25 ing out its duties. Any such detail shall not interrupt

1 or otherwise affect the civil service status or privi-
2 leges of the Federal employee.

3 (5) TECHNICAL ASSISTANCE.—Upon the re-
4 quest of the Commission, the head of a Federal
5 agency shall provide such technical assistance to the
6 Commission as the Commission determines to be
7 necessary to carry out its duties.

8 (6) USE OF MAILS.—The Commission may use
9 the United States mails in the same manner and
10 under the same conditions as Federal agencies and
11 shall, for purposes of the frank, be considered a
12 commission of Congress as described in section 3215
13 of title 39, United States Code.

14 (7) OBTAINING INFORMATION.—The Commis-
15 sion may secure directly from any Federal agency
16 information necessary to enable it to carry out its
17 duties, if the information may be disclosed under
18 section 552 of title 5, United States Code. Upon re-
19 quest of the Chairman of the Commission, the head
20 of such agency shall furnish such information to the
21 Commission.

22 (8) ADMINISTRATIVE SUPPORT SERVICES.—
23 Upon the request of the Commission, the Adminis-
24 trator of General Services shall provide to the Com-

1 mission on a reimbursable basis such administrative
2 support services as the Commission may request.

3 (9) PRINTING.—For purposes of costs relating
4 to printing and binding, including the cost of per-
5 sonnel detailed from the Government Printing Of-
6 fice, the Commission shall be deemed to be a com-
7 mittee of the Congress.

8 (f) REPORT.—Not later than 18 months after the
9 date of the enactment of this Act, the Commission shall
10 submit a report to the President and the Congress which
11 shall contain a detailed statement of only those rec-
12 ommendations, findings, and conclusions of the Commis-
13 sion that receive the approval of at least 11 members of
14 the Commission.

15 (g) TERMINATION.—The Commission shall terminate
16 30 days after the date of submission of the report required
17 in subsection (f).

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